

National Institute of Mental Health Alliance for Research Progress July 25, 2005, Bethesda, MD

Introduction

The National Institute of Mental Health (NIMH) held its Alliance for Research Progress Summer Meeting Monday, July 25, 2005 at the Hyatt Regency Washington on Capitol Hill in Washington, DC. This third meeting of the Alliance for Research Progress was devoted to continuing an active dialogue with representatives of NIMH's patient and family constituency groups and to discussing a research agenda attuned to the needs of people with mental illnesses. Invitees embodied wide-ranging perspectives including those of consumers, providers of mental health services, family members, and others.



NIMH Director Thomas R. Insel, M.D., opened the meeting with a discussion of the "State of the NIMH." Presentations on the Annapolis Coalition's vision for the future of education and training for the behavioral health workforce, SAMHSA's progress in transforming America's mental health care system, the need for cultural competency in the healthcare system, and addressing health disparities followed. Two discussants, a psychiatrist and a researcher, gave examples from their work to illustrate the importance of developing a research agenda focused on the needs of all people with mental illnesses.

Speakers

Thomas R. Insel, M.D., "Welcome and State of the NIMH"

Dr. Insel updated Alliance members on current activities, research advances, and new directions for NIMH. He began by saying "NIMH faces an enormous challenge in fulfilling its mission to reduce the burden of mental and behavioral disorders through research on the mind, brain, and behavior." The need is vast. According to the 2002 WHO World Health Report, mental disorders account for four of the top five causes of premature death and disability among 15-44 year olds in the Western world.

Dr. Insel made the following additional points about the burden of mental illness: (1) more than 50 percent of all mental health expenditures are paid for by the public sector — Medicaid, Medicare, state and local government (President's New Freedom Commission Report on Mental Health); (2) many individuals with mental disorders are in the criminal justice system, in nursing homes, in schools, homeless, in primary care settings, or in rural areas, (National Co-morbidity Survey Replication, Kessler et al.); (3) qualified mental health providers are rarely present in any of the settings described

above; and (4) no drugs with new mechanisms of action have been developed to treat mental illnesses since the 1950s.

Despite these challenges we are moving forward, continued Insel. He indicated that SAMHSA recently issued a report, *Transforming Mental Healthcare in America: the Federal Mental Health Action Agenda*, which represents the first year of a multi-year effort to transform the mental health service delivery system in America, as called for in the President's New Freedom Commission Report on Mental Health (<http://www.mentalhealthcommission.gov/reports/reports.htm>). NIMH is working with the Substance Abuse and Mental Health Services Administration (SAMHSA) to implement the items described in this report. More details are included in the speaker summaries.

Dr. Insel shared with Alliance members a research vision for recovery leading to personalized healthcare. Currently mental disorders are diagnosed by looking only at symptoms and are usually treated by episode (trial and error). Dr. Insel described a movement towards a system of personalized care that includes strategic prevention and more effective treatments. Two processes are needed before this can happen.

1. Development of Revolutionary technologies that would allow more targeted mental healthcare. Examples include neuroimaging, genomics, proteomics, molecular diagnostics, and clinical genomics.
2. Evolutionary Practices — We need more evidence based practices, better dissemination, and increased access to care in rural underserved populations.



Dr. Tom Insel, NIMH, updates Alliance members on NIH activities

However, there is a lack of true understanding of the underlying causes of mental disorders, said Insel. This information is needed to develop better diagnostic measures that will allow for treatment of the core problem.

Dr. Insel then gave participants a brief update on NIH activities. He began with a description of the NIMH fiscal year 2006 President's Budget request of \$1.4 billion. This represents an increase of \$15 million or 1.1 percent over

the fiscal year 2005 request. Dr. Insel described the current budget situation as a leveling off of the "doubling" that occurred from 1998-2003.

He added that many grants first funded in 1999 will be ending in 2006 and this will free up additional funds. Detailed information on the NIMH 2006 fiscal year budget request is available on the NIMH Web site at <http://www.nimh.nih.gov/about/budget.cfm>.

Dr. Insel then turned to the topic of *NIH Reauthorization*. The last reauthorization for NIH was in 1993. In response to the IOM Report *Enhancing the Vitality of the NIH: Organizational Change to Meet New Challenges* (2003), members of Congress want to know if the current NIH organizational structure is effective, efficient, and strategic. The

House Committee on Energy and Commerce, chaired by Congressman Joe Barton (R-TX), held a reauthorization hearing on July 19, 2005 to address these questions. NIH Director Dr. Elias A. Zerhouni was the only witness (his testimony is available at <http://olpa.od.nih.gov/hearings/109/session1/summaries/reauthorization.asp>).

Currently there is a “discussion draft” of a reauthorization bill for NIH that calls for 4 separate appropriations that would cover all of NIH: (1) the NIH Office of the Director, (2) a new division for program coordination in the OD, (3) all mission-specific institutes, and (4) science-enabling ICs.

Dr. Insel then described the new *NIH Public Access Policy*. This policy is designed to give the public better access to research publications resulting from NIH-funded research by establishing a comprehensive, searchable electronic archive of publications resulting from NIH-supported research. Under the policy, NIH-funded investigators are strongly encouraged to submit their manuscripts of research results at the time of acceptance for publication to the National Library of Medicine’s PubMed Central, an electronic database. He described this policy as a real “culture” change for NIH and as a way NIH can “level the playing field” by making research results funded by NIH quickly accessible to the general public. More information on the policy is available on the NIH Public Access Web site at <http://www.nih.gov/about/publicaccess/index.htm>.

Dr. Insel alerted Alliance members that results from the following large multi-center NIMH funded trials are forthcoming.

- STEP-BD — Systematic Treatment Enhancement Program for Bipolar Disorder
- CATIE — Clinical Antipsychotic Trials of Intervention Effectiveness
- STAR*D — Sequenced Treatment Alternatives to Relieve Depression

Information on study results from the CATIE trial is available on the NIMH Web site.



Dr. Michael Sesma, NIMH, converses with Ms. Marcela Gaitan, National Alliance for Hispanic Health

Dr. Insel also shared recent results from the NIMH National Comorbidity Survey Replication study — a household survey of more than 9000 adults designed to determine the prevalence of various mental disorders. The results were shocking to people outside of the mental health community. Researchers found that about half of all individuals in the United States will have a mental illness in their lifetime and about one fourth will have a mental illness in a given year (Kessler et al. Arch Gen

Psychiatry. 2005; 62:593-602, 617-627). Dr. Ronald Kessler, the principle investigator, found that the delay between onset of mental disorder and first treatment is typically 6 to 12 years, depending on the disorder. A detailed description of the survey findings were published in the June 2005 issue of the *Archives of General Psychiatry*.

Dr. Insel then described the following NIMH initiatives in schizophrenia cognition research.

- In January 2005, NIMH, FDA, and participants from the NIMH MATRICS Initiative (Measurement and Treatment Research to Improve Cognition in Schizophrenia) held a meeting to focus on a process for developing or identifying evidence-based measures and methodologies to establish the efficacy of treatments that target negative symptoms of schizophrenia. Now almost complete, the NIMH MATRICS, a cognitive battery development process, was the focus of a December 2004 special issue of *Schizophrenia Research*.
- Following a nationwide “call for nominations” in November 2004, the Treatment Units for Research on Neurocognition in Schizophrenia (TURNs) Compound Selection Committee reviewed over twenty nominations of novel therapeutic compounds for treating the cognitive deficits of schizophrenia were proposed and two were selected for initial clinical efficacy trials.
- Report on Cognition in Schizophrenia — Consensus guidelines for the evaluation of co-therapies and broad-spectrum agents targeting condition in schizophrenia are outlined in a report of the 2004 FDA-NIMH-MATRICES Workshop on Clinical Trial Design for Cognition in Schizophrenia. A summary of the workshop is available at the online *Schizophrenia Bulletin*.
- Schizophrenia Research Forum Web site — To speed up the development of better treatments, prevention, and eventual cures for schizophrenia, a new online scientific forum for schizophrenia researchers was launched. The intent of this online community is to present current news on schizophrenia and provide a forum for discussing research and exchanging new ideas. The site will also maintain databases, directories, research tools, and links to online resources.
- Schizophrenia Bulletin — The recent issue of the *Schizophrenia Bulletin* featured a special section on mental illness stigma, “Building Mental Illness Stigma Research,” edited by two NIMH scientists, Drs. Emeline Otey and Wayne Fenton.

Dr. Insel concluded with a review of NIMH Public Outreach highlights.

- First Coalition for Research Progress Meeting: The Institute convened its first meeting of constituent professional organizations — the Professional Coalition for Research Progress — in March 2005. A meeting summary is available on the NIMH Web site at <http://www.nimh.nih.gov/Outreach/roundtablemenu.cfm>.
- Real Men Real Depression: NIMH expanded the reach of this program — with production of new public service announcements and informational materials featuring two Native American men from the Lakota Sioux in South Dakota — and a new Spanish-language public service announcement for television, radio, and print. Information on the campaign is available at <http://menanddepression.nimh.nih.gov/>.
- Sixth Annual Meeting of the NIMH Outreach Partners Program: The NIMH Outreach Partnership Program — a nationwide initiative that brings together national and state organizations to help bridge the gap between research and clinical practice — held the annual meeting of its 51 outreach partners in early

April in Omaha, Nebraska. Additional information on the NIMH Outreach Partnership Program is available at <http://www.nimh.nih.gov/outreach/partners/index.cfm>.

Leighton Huey, M.D., “The Annapolis Coalition”



Dr. Leighton Huey, the Annapolis Coalition, talks to Alliance members

Dr. Leighton Huey, the Birnbaum/Blum Professor, Chairman, and Training Director at the University of Connecticut and Member of the Board of the *Annapolis Coalition on the Behavioral Health Workforce*, stated the charge of the Coalition — to create a national plan of action keying on the President’s *New Freedom Commission* and the Institute of Medicine’s *Crossing the Quality Chasm*, to prove and strengthen the multidisciplinary mental and behavioral health workforce. The initial round

of reports from various national task forces are due in December of 2005 with plans to host a National Summit of Workforce in April of 2006. The Annapolis Coalition’s mission is to build a national consensus on the nature of the workforce crisis and to promote improvements in the quality and relevance of education and training by identifying and implementing change strategies, particularly in the area of training at both pre-professional and established workforce levels. To move this agenda forward, SAMHSA has contracted with the Annapolis Coalition to work with a broad constituency of stakeholders to develop a National Strategic Plan on Behavioral Health Workforce Development.

According to Dr. Huey several key issues need to shape the new workforce — location (i.e., where is the workforce?), balance (no one discipline can do everything), and public subsidies (connecting public dollars to services). He outlined the ingredients needed to achieve the Coalition’s vision for the future of behavioral health care and services — clinicians who are well trained to conduct comprehensive assessment, treatment and follow-up with patients, evidence-based practice where clinicians track improvement of outcomes in patients, shared decision making between practitioners and consumers/patients, patient and family focused treatment that includes patients and families as part of the treatment team, new economic models to replace traditional fee-for-service, pay for performance within quality improvement, interdisciplinary seminars as standard training, appropriate changes in accreditation standards, funding systems that support and sustain innovation, and multidisciplinary integrated training teams placed in strategic areas. More information about the Annapolis Coalition is available on their Web site at www.annapoliscoalition.org.

Suzanne E. Vogel-Scibilia, M.D., “Discussant”



**Dr. Suzanne E. Vogel-Scibilia, Beaver County
Psychiatric Services**

As a practicing clinical psychiatrist, a person with bipolar disorder, and an advocate, Dr. Vogel-Scibilia brought a unique perspective to the discussion. She began by describing her background — she lives in rural Pennsylvania and mental illness runs in her family (her parents and children all have mental illnesses). She is one of the few psychiatrists who openly shares her diagnosis — bipolar disorder — with her patients and colleagues.

According to Dr. Vogel-Scibilia a bright future for mental health in America involves the kind of strategic planning currently underway by the Annapolis Coalition. She shared her concerns about the mental health field based on her direct experience as both a provider and a patient. These concerns include the following — a shortage of providers, lack of adequate training, stigma associated with mental illnesses, suboptimal care for patients, fragmented services, development of a two-tier system based on income level, and the use of evidence-based practices as a way to deny care. She gave examples from her practice to illustrate these concerns. Because of a shortage of providers, in her town of Beaver, Pennsylvania there is an 8-12 week waiting list to see a child psychiatrist and often pediatricians have to step up and fill in the gaps.

Dr. Vogel-Scibilia brought up what she views as another serious problem — people with the most severe mental illnesses are the least served in the current system.

“The correlation between severity of mental illness and percentage of people served is the opposite of what it needs to be,” said Vogel-Scibilia. She also pointed out that often master’s level counselors are the providers who spend the most time with patients

and their level of training may not always be adequate to deal with patients — especially those who suffer from severe forms of mental disorders.

Dr. Vogel-Scibilia strongly believes in consumer-driven healthcare. She believes her patients should be actively involved in their own treatment; she also recognizes that roadblocks exist. For example, there is no body of literature that explains how to develop a consumer-driven recovery plan. Dr. Vogel-Scibilia worries that the focus on evidence-based practices may be used to restrict services because only treatments that are rigorously studied and proven to be ‘evidence-based’ will be covered under insurance. “In the field of eating disorders the lack of an evidence base is often used to deny treatment,” agreed Dr. Insel. Lastly, Dr. Vogel-Scibilia strongly recommended that Alliance members work together by advocating for everyone with mental illness instead of focusing solely on their organization’s target population.

A. Kathryn Power, M.Ed., “Transforming America’s Mental Health Care”



Ms. Kathryn Power, CMHS, talks about transforming mental health care in America.

Ms. A. Kathryn Power, M.Ed., Director of SAMHSA’s Center for Mental Health Services (CMHS), spoke about transforming America’s mental health care system as recommended in the President’s New Freedom Commission Report on Mental Health. She discussed the implications of a new report that outlines plans to begin implementing the Commission report.

This new report, entitled *Transforming Mental Healthcare in America: the Federal Mental*

Health Action Agenda came out in late July. “This report represents the beginning of a multi-year effort to transform the mental health service delivery system in America,” said Ms. Power. The Federal Partners Work Group developed the principles that underlie this federal action agenda — a focus on desired outcomes, community-level models of care (cultural competence), increased cost-effectiveness and reduced barriers to care, use of research findings to influence service delivery (NIMH working with SAMHSA); and promotion of innovation, flexibility, and accountability at all levels of government (local, state, federal). The full report includes over 70 action steps and is available electronically on the SAMHSA Web site at

http://www.samhsa.gov/Federalactionagenda/NFC_TOC.aspx.

According to the report’s framers the Action Agenda is a living document that will move the Nation closer to the day when adults and children with serious mental illnesses or emotional disturbances will live, work, learn, and participate fully in their communities. Ms. Power emphasized the groundbreaking nature of this report — it includes a broad set of government agencies committed to supporting the transformation of the mental healthcare system.

The following agencies make up the *Federal Partners Workgroup* — the NIH, the U.S.



Kathryn Power converses with Alliance participants.

Centers for Disease Control and Prevention, CMHS, the U.S. Food and Drug Administration, the U.S. Departments of Education, Housing and Urban Development, Department of Justice, Department of Labor and Veterans’ Affairs, and the Social Security Administration (SSA). “This cross agency collaboration creates a model of what should happen at both the federal and state levels,” said Ms. Power.

Ms. Power talked about the recent efforts of the *Federal Partners Workgroup* to decrease homelessness and increase employment for people with mental illnesses. “The ultimate goal of transformation is to create a mental health system that is consumer-driven,” said

Ms. Power. Her agency focuses on ensuring that mental health services and treatments are consumer and family centered. “The center of gravity for this transformation is at the state and local level where the greatest opportunity to make a difference exists,” said Ms. Power. Ms. Power gave examples of CMHS’ efforts at the state level — CMHS is looking at innovative ways to use technology to give states greater access to support services and is working to develop a prototype for states to use. Her organization also has a Mental Health Transformation State Incentive Grant Program that provides seed money to help states develop infrastructure to meet the comprehensive needs of consumers and families.

As part of this transformation of state mental health systems CMHS is partnering with the National Governor’s Association Center for Best Practices, continued Ms. Power. Four regional meetings called *Transforming State Mental Health Systems* will take place across the United States. These meetings are designed to bring together teams of individuals to create a vision for transformation in their states. The goal of these meetings is to reach consensus on priorities and strategies for achieving their vision, said Ms. Power.

Ms. Power also talked about National Outcome Measures for Mental Health developed by CMHS. Last year her organization incorporated these national outcome measures, or NOMs, for mental health into their state mental health block grant reporting requirements. The national outcome measures reflect a transformed view of effective mental health care because they focus on positive outcomes for consumers as described by consumers. Examples of outcome measures include — a decrease in mental illness symptoms and improvement in functioning, an increase in employment, a decrease in criminal justice involvement, increased access to services, and use of evidence-based practices.

Ms. Power told Alliance members about six evidence-based practice implementation resource kits that her agency produced to encourage the use of evidence-based practices in mental health. Toolkit topics include illness management and recovery, medication management approaches to psychiatry, assertive community treatment, family psychoeducation, supported employment, co-occurring disorders, and integrated dual diagnosis treatment. “It is important for you to know that these toolkits were developed based on a consensus group of consumers and families who identified these as the most important practices that practitioners need to implement,” stated Ms. Power.

Currently more than 50 community health programs are evaluating their use of the toolkits, which can be downloaded from SAMHSA’s Web site at <http://www.mentalhealth.samhsa.gov/cmhs/communitysupport/toolkits/about.asp> and can be ordered by calling 1-800-789-2647.

“As part of this era of transformation, recovery is now defined as a process through which a person achieves independence, self-esteem, and a meaningful life in the community. This does not necessarily mean a cure,” said Ms. Power. She also reminded participants that it takes 20 years to move from evidence-based research to care.

Honorable Sue Myrick (R-NC), “A View from Capitol Hill”

Unfortunately, the Honorable Sue Myrick (R-NC) had a personal emergency and was unable to speak at the Alliance meeting. “We have no greater supporter than Congresswoman Sue Myrick-- a tremendous advocate and champion,” said Dr. Insel. He told Alliance members that Representative Myrick plans on holding a series of hearings this fall to raise awareness about mental health and mental illness.

William A. Vega, Ph.D., “Cultural Competence: Diversity Counts”

Dr. Vega is a Professor of Psychiatry at the Robert Wood Johnson Medical School University of Medicine and Dentistry of New Jersey. He is also the president of National Latino Council on Alcohol and Tobacco Prevention and co-principal investigator on the National Latino/Asian Epidemiological Survey. Dr. Vega talked about what cultural competence is and is not and how it can be used to transform mental health services. He began by sharing the following as examples of unrealistic assumptions about cultural competence.

- It can remedy disparities in treatment.
- It is easily dispensed in short training sessions.
- Client outcomes can be improved without disturbing “business as usual” such as patient manager routines of behavioral health providers.
- It will not cost much money.
- It satisfies the ethical requirement for responsiveness to diversity.



Dr. William Vega, Robert Wood Johnson Medical School, University of Medicine and Dentistry of New Jersey.

Dr. Vega suggested to Alliance members that cultural competence is really about quality of care. He defined quality of care as the capacity to deliver appropriate and effective treatment. “Cost, knowledge, acceptance in professional groups, and organizational resistance are the major obstacles to achieving quality of care.

A lack of cultural competence adversely affects quality of care,” continued Vega. For example, African Americans are twice as likely to be misdiagnosed compared with European

Americans. We are starting from a low baseline in terms of research in this area. Cultural competency must become an organizational issue. It is not about having employees take a 2-hour course,” concluded Vega.

Dr. Vega talked about latent organizational resistance to cultural competence and gave several reasons for this resistance — cultural competence does not have a demonstrated effect on cost or patient satisfaction, and stakeholders want to know what will change in their organizations if they have more cultural competency. For example, will it increase treatment adherence?

Dr. Vega also gave suggestions for combating organizational resistance — mainstreaming cultural competence into core competencies such as managing impulsivity and suicide, post traumatic stress disorder, group therapy. “Cultural competence must fit into healthcare organizational priorities while it also seeks to change them,” asserted Vega. For example, cultural competence could be linked to organizational goals such as accreditation, continued Vega. One way to start this process is by introducing performance indicators with accountability measures, explained Vega. “Cultural competence will become part of the culture of health care when we reach a tipping point. The key to improving quality of care for Latinos will be training ourselves to train majority group professions. We are the change agents,” concluded Vega.

Ernest Marquez, Ph.D., “NIMH Recent Efforts to Address Disparities”



Dr. Ernest Marquez, Director of the NIMH Office of Special Populations and Rural Mental Health Research (OSP/RMHR), explained the purpose of his office. OSP/RMHR ensures that the NIMH training, service delivery, and research programs reflect the mental health needs of women, minority populations, and people living in rural and frontier areas of the U.S. Reducing mental health disparities is a key objective of his office which includes the

Women’s Mental Health Program, the Mental Health Research Scientist Development Program, the Health Disparities Program, and the Rural Mental Health Program. A detailed listing of research and training programs supported by OSP is available at <http://www.nimh.nih.gov/researchfunding/training.cfm>.

Michele R. Cooley, M.Ed., Ph.D., “Cultural Competence and Addressing Mental Health Disparities”

Dr. Michele Cooley is a licensed psychologist and Associate Professor in the Department of Mental Health, Bloomberg School of Public Health at the Johns Hopkins University. Her research focus is the behavioral and emotional consequences for children exposed to violence. Dr. Cooley described to Alliance members an NIMH funded pilot study called the FRIENDS Anxiety Prevention Study.

FRIENDS is a school-based preventive intervention that was used with 3rd through 5th grade inner-city children exposed to community violence who are at risk for anxiety disorders. Dr. Cooley illustrated how research can serve public health, specifically members of racial and ethnic minority groups. For example, all potential study participants for FRIENDS are screened using the Children’s Depression Inventory.



Dr. Michele R. Cooley, Johns Hopkins University, describes cultural competence and health disparities.

Children whose responses indicate thoughts of suicide are then screened by a psychologist to assess level of risk and appropriate referrals are made. Dr. Cooley believes she and other researchers are providing a service to the community — these children may not otherwise receive mental health services. She shared with Alliance members that monitoring the safety of children and providing appropriate referrals is part of the responsibility that goes along with doing community-based research.

She talked about the need for cultural competence in the mental health field and the difference between cultural competence and cultural sensitivity. Dr. Cooley — using a SAMHSA definition — identified culture as shared values, traditions, customs, arts; and history of a group of people unified by characteristics such as age, gender, race, ethnicity, spirituality, language, English language proficiency, literacy levels, sexual orientation, and more. She described cultural sensitivity as an awareness of the cultures around us.

Dr. Cooley continued the discussion on health disparities that Drs. Marquez and Vega began. She suggested that mental health disparities could be reduced through an increase in cultural competence. Dr. Cooley suggested how to make this happen — link cultural competence to organizational goals, such as accreditation or NIMH funding.

She also suggested developing an on-line course that trains researchers in cultural



Meeting Attendees talk during a break.

sensitivity and enhances multicultural skill awareness. The outcome would be a *certificate in cultural competence*, similar to the certificate required in human subjects research ethics.

By ensuring that NIMH program staff and those persons who serve as NIH/NIMH initial review groups are well represented by diverse racial/ethnic/cultural groups (and, once a cultural competence certificate program is established, that all IRG members are certified).

She also suggested that patient advocate organizations use their expertise in influencing policy change to train mental health researchers. This in turn might reduce the lag time in translating solid science to practice, continued Cooley. It is achievable, not as an end-point but as an ever developing process, concluded Cooley.

Dr. Cooley also expressed her support for the new NIMH recruitment policy with Alliance members. This policy is designed to monitor recruitment of participants in NIMH-sponsored clinical research studies that expect to enroll 150 or more people. Its purpose is to ensure that realistic recruitment targets are established at the beginning of a project, and that these targets are met throughout the course of the research.

The Web site for the new policy is

<http://www.nimh.nih.gov/researchfunding/nimhrecruitmentpolicy.cfm>.

Dr. Insel thanked Dr. Cooley for bringing up this topic and emphasized that clinical trial recruitment is a big issue for NIMH. A research base that is applicable for all Americans

must involve all racial and ethnic groups, said Insel. Dr. Cooley agreed and added that research participants “vote” with their pens (consent rates) and their feet (attrition). Successful researchers who work with ethnic/racial minority groups become quickly aware of strategies to maximize participation rates and minimize attrition, many of which involve culturally sound practices, concluded Cooley.

Discussion Periods

During the discussion periods, Alliance participants had the opportunity to direct comments and questions to the NIMH Director, and to engage the presenters in discussion on pressing needs in the mental health field.



Mr. Michael Faenza, National Mental Health Association.

Mr. Michael Faenza, President of the National Mental Health Association, began by responding to Dr. Insel’s update on the recently introduced reauthorization bill for NIH. Mr. Faenza’s organization submitted a letter to the Chairman of the House Committee on Commerce and Health, the Honorable Joe Barton, to express serious concerns about the reauthorization bill.

“We are concerned that language in the bill would put too much power in the NIH Director’s Office,” said Faenza. “This would put NIMH at risk by injecting more politics into the process. My organization is concerned that the issues of science will no longer be the center of decisions,” concluded Faenza.



Ms. Sue Levi-Pearl, Tourette Syndrome Association.

Ms. Sue Levi-Pearl, Vice President of Medical and Scientific Programs for the Tourette Syndrome Association, Inc., supported Mr. Faenza’s concerns and added, “We need to realize that no matter what administration is in power there is a problem with decision-making being in the hands of one political appointee.”

other institutes, such as neurology would be an improvement. She added, “The real tragedy is that it takes 10-15 years to move from science to practice.”

Ms. Valerie Porr, President of TARA- the National Association for Personality Disorders,



Dr. Sherry Marts, Vice President of Scientific Affairs for the Society for Women’s Health Research shared her opinion on the importance of including a screening initiative as part of the

President's Freedom Commission Report. She acknowledged that this is a sensitive topic — some skeptics view it as a way to get more children into the mental health system, whether they actually need mental health services or not.

The discussion turned to reimbursement for mental health services. Mr. Faenza described the current cuts to Medicaid reimbursements in the states as a “fast moving train on a collision course.” Dr. Insel agreed that this is a most pressing public policy issue and he said NIMH is trying to develop partnership with CMHS/SAMHSA to address this issue.

NIMH, in partnership with CMHS, recently funded projects to look at the impact of Medicaid reimbursement on the states, continued Insel. Ms. Porr spoke about the lack of reimbursement for individuals with personality disorders.

Alliance members shared both concerns and creative ideas for making research and services more focused on the needs of people with mental illnesses. Ms. Marcela Gaitán, from the National Alliance for Hispanic Health, expressed concern about the lack of health professional representation from racial/ethnic populations in the mental health field. Having more doctors and other health professionals of similar cultural backgrounds to the community members they treat would improve the access and quality of treatment, concluded Ms. Gaitán.



Ms. Sue Bergeson, Depression and Bipolar Support Alliance, and Mr. Marc Lerro, Eating Disorders Coalition.

Ms. Sue Bergeson, Vice President of the Depression and Bipolar Support Alliance (DBSA), suggested that consumers and families be trained and hired as part of the healthcare workforce. “Consumers should teach part of the curricula in medical schools, be used as peer educators, and be a part of every recovery plan. The current workforce needs retraining” concluded Bergeson.

Ms. Bergeson also shared results from a recent survey her organization administered to 1,000 people with mental illnesses. They were asked to describe what they want most in their healthcare services. According to Bergeson, the most frequent responses were as follows — providers who listen to me, thorough explanations of what is going on, treatment that looks at my whole life not just medication and that builds on my strengths instead of just focusing on the illness, and care that provides hope.

Dr. Terence Keane, Director of Behavioral Science Division of the National Center for Post-Traumatic Stress Disorder, suggested that his organization work collaboratively with federal institutions such as the NIMH, CDC, and SAMHSA, to help returning military personnel and their families manage the psychological consequences of service in the current war on terror. “The psychological effects of this war on terror are serious and relatively common and I believe we will see increased psychological casualties in the future,” concluded Keane.

Ms. Sheila Rabaut from NARSAD Mental Health Research Association, encouraged Alliance members to attend their 2006 gala on February 25 and their symposium on February 26. More information is available on their Web site.

Dr. Insel concluded the meeting by emphasizing the important of NIMH's partnerships with voluntary groups. "We are focused on being good stewards of the public's money and we need your help to transform the mental health system," said Insel. In this spirit of partnership, Ms. Gemma Weiblinger, Director of the Office of Constituency Relations and Public Liaison at NIMH, encouraged Alliance members to join the NIMH Outreach Partnership Program National Network by e-mailing NIMHPatners@mail.nih.gov.



Samantha Helfert, NIMH Outreach Partnership Program Liaison, shows Alliance Members new Web site for National Partners.

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November 2005